

## PE1404/DD

Petitioner Letter of 30 September 2013

### Public Petitions Committee Meeting 1/10/13

#### PE01404: Access to Insulin Pump Therapy

##### Missed Targets:

Diabetes UK Scotland welcomes the release by Scottish Government of the most recent data in relation to insulin pump therapy. There has been a lot of hard work carried out to try and achieve the targets, with a fourfold increase since 2011. However there is a lot of variation with some Health Boards making good progress whereas others have stalled and one board has seen a decrease in numbers. We understand this may be due to children transferring to adult services and we would encourage reports to note this kind of impact.

Diabetes UK Scotland has concerns that boards [excluding NHS Highland and Lanarkshire as they are under specific performance support arrangements] will reach the 25% level of provision by March 2014 - and *maintain* this beyond 2015. We appreciate the hard work being carried out – the concern is that given the numbers achieved to date, there would need to be a marked and significant increase to meet the deadlines set. For example:

- NHS Grampian over a similar period from December 2012 to August 2013, 8 months, provided provision for **7** new under 18 year olds. To achieve the 25% commitment by March 2014 over a 7 months period there will have to be **40** new under 18 year olds on pumps, a increase of 5.7 times the rate over the previous period.
- In NHS Forth Valley, a similar picture emerges; over the previous eight months from December 2012 to August 2013, there were **4** new under 18 year olds trained and provided insulin pumps. For the period from September 2013 to December 2013, *three months*, there will need to be an addition **18** new under 18 year olds on insulin pumps.

We do not think that the deadlines themselves are overly ambitious – the support and investment made available to health boards reflects the targets set – however we are aware that several health boards, for various reasons, saw a slow start to achieving the targets. Will we see another missed set of targets in six months time or are Boards now in a definite position to deliver? It would be helpful to receive clarity on this and what will happen if Boards do not meet these new deadlines.

In addition, we believe that the reporting of how a Health Board is progressing could be improved. The monthly reports are very helpful and we appreciate the communication currently happening with Diabetes UK Scotland on the reporting. As a result we have been able to analyse the figures and ascertain whether Health Boards are still on track towards their deadlines. Transparency around this is critical for patient confidence in their Health Board. It is important that there is a clear mechanism for Health Boards to highlight within their reports and communications when their initial planned trajectory is affected by the numbers achieved each month and that this information is brought to the attention of the Improvement Team [or whoever is most appropriate] so that support can be accessed and provided at the earliest stage.

There are two Health Boards that have an extra year extension where we hope that this extra time will bear fruit. NHS Highland and Lanarkshire have a substantial path to navigate in ensure that they reach the 25% target and Diabetes UK Scotland urges the committee to examine the implications for the delay in young people missing out on this life changing resource.

Diabetes UK Scotland has been attending the patient information meetings with the NHS Highland and recommends the events as a useful event with a good mix of information, inspirational interaction with those who have benefited from a pump, and practical hands on opportunities for children and their families who could benefit from a pump. Hopefully with the continuation of these events it should help the Health Board reach the commitment. We would urge Health Boards struggling to meet their insulin pump obligations to consider this approach and for Highland to build it in as core to their patient engagement work for pumps and for other services.

As the majority of NHS Health Boards missed their targets, Scottish Government extended the deadline by 1 year to ensure that all Health Boards, excepting NHS Lanarkshire and Highland, will have achieved the goal. Given the importance of meeting the targets and ensuring children can access this treatment in a timely fashion, we are interested to hear how this new deadline will be assured to be met.

### **Conclusion:**

Diabetes UK Scotland appreciates the efforts the Scottish Government and Health Boards have made to achieve this target. In particular, we recognise the hard work carried out by frontline NHS staff to deliver. The work of the Improvement Team has been a significant plus in supporting Health Boards in their task and delivering for patients. The committee's work has been invaluable in highlighting and holding to account Scottish Government and Health Boards. However there continues to be concern around how transparent and realistic health boards are in devising their trajectory of pump delivery. We appreciate the challenge made to health boards on the original targets and a year to meet them – however, we could now see some

health boards take up to three years to deliver. This is time lost to patients and their families in accessing this treatment. Diabetes UK Scotland hopes that the committee will examine the achievability of these figures.

We would ask the committee to consider keeping the petition open and receive monthly update reports from the Scottish Government to establish progress for children and adult services.

### **The Questions for the Committee:**

- Given the slippage experienced to date, how confident can we be about the new deadlines being met?
- What mechanisms are in place to monitor and support Health Boards towards meeting their targets? Are there any improvements that can be made to reporting mechanism to ensure easy identification of issues at an early stage for successful intervention to be made?
- What assurances can be given to parents that, once their child has gone through the initial transition on to a pump, there will be accessible and ongoing support?
- What is the national position on how families can access pump consumables – we have heard of parents being told they can only have one or three month supplies that they will need to fund the batteries themselves, and that while the devices are owned by Health Boards families must incur the cost of insuring the pumps themselves?